



Complete Summary

GUIDELINE TITLE

Identification, referral, and support of elders with genetic conditions.

BIBLIOGRAPHIC SOURCE(S)

Schutte DL. Identification, referral, and support of elders with genetic conditions. Iowa City (IA): University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core; 1999. 30 p. [11 references]

COMPLETE SUMMARY CONTENT

SCOPE

METHODOLOGY - including Rating Scheme and Cost Analysis

RECOMMENDATIONS

EVIDENCE SUPPORTING THE RECOMMENDATIONS

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

QUALIFYING STATEMENTS

IMPLEMENTATION OF THE GUIDELINE

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT

CATEGORIES

IDENTIFYING INFORMATION AND AVAILABILITY

SCOPE

DISEASE/CONDITION(S)

Genetic conditions common to or occurring primarily in the elderly population, including:

- Huntington's disease
- Alzheimer's disease
- Breast cancer
- Prostate cancer
- Familial adenomatous polyposis
- Parkinson's disease
- Glaucoma
- Macular degeneration
- Primary psychiatric disorders, such as bipolar disorder, major depression, and schizophrenia
- Hemochromatosis

GUIDELINE CATEGORY

Management
Risk Assessment

CLINICAL SPECIALTY

Geriatrics
Medical Genetics

INTENDED USERS

Advanced Practice Nurses
Nurses

GUIDELINE OBJECTIVE(S)

To provide guidelines for the assessment and management of nursing needs related to the genetic aspects of health conditions in the elderly.

TARGET POPULATION

Elderly individuals at increased risk for a genetic condition or the need for genetic services, including:

- Elderly individuals diagnosed with a health response, disorder, or condition with a known genetic component
- Asymptomatic adults with a positive family history of a condition with a known genetic component
- Elderly individuals diagnosed with or exhibiting a positive family history of common health conditions with an early-onset
- Elderly individuals diagnosed with or exhibiting a positive family history of a neurodegenerative disorder

INTERVENTIONS AND PRACTICES CONSIDERED

1. Identification
 - Comprehensive family health history
 - Genetics psychosocial assessment
 - Establishment of mutual goals
2. Referral
 - Referral for confirmation of diagnosis
 - Referral for specialized genetic services
 - Referral for specialty mental health services
3. Support
 - Advocacy
 - Reinforcement of specialty interventions
 - Teaching
 - Psychosocial counseling
 - Ongoing assessment and goal setting

MAJOR OUTCOMES CONSIDERED

- Client satisfaction with family history interview and psychosocial assessment interview
- Documentation in genetics assessment flow sheet; documentation of appropriate referral for specialty genetic or mental health services.

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

The guideline developer performed searches of electronic databases, including Medline (U.S. National Library of Medicine) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and performed handsearches of published literature.

NUMBER OF SOURCE DOCUMENTS

25 source documents

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

This guideline was reviewed by a pair of external reviewers: (1) Cindy Prows, MSN, RN, Adjunct Faculty, Clinical Nurse Specialist, Human Genetics Department, Children's Hospital Medical Center, Cincinnati, Ohio; (2) Janet Williams, PhD, RN, Associated Professor, The University of Iowa College of Nursing, Iowa City, Iowa.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

I. Identify

Identification of individuals or families experiencing or at risk for a genetic condition is an important contribution of gerontological nurses. Assessment of the family health history, family knowledge and readiness to learn, and family goals and desired outcomes are important elements of screening for genetic risks and initiating appropriate interventions.

Comprehensive Family Health History

The family health history is obtained by interview in order to construct a picture of family health for 3 to 4 generations when possible. Family histories are best recorded as pedigrees. Pedigrees use a standardized set of symbols to show relationships between individuals as well as their health status.

Indications for referral for specialized genetic counseling services include:

- family history of a condition with a known genetic component, such as Huntington disease or Alzheimer disease.
- presence of a condition that follows a recognizable pattern of inheritance (e.g. autosomal dominant or recessive, X-linked dominant or recessive).
- new diagnosis or family history of an earlier than expected onset in common illnesses, such as breast, ovarian, prostate, or colon cancer; cardiovascular disease, and Alzheimer's disease.
- requests for information regarding genetic testing or gene therapy options.

Genetics Psychosocial Assessment

A second important element of an assessment for genetics-related health needs is the determination of an individual or family's current level of knowledge, readiness to learn, coping strategies, and communication styles.

Establish Mutual Goals

A third element of assessment for genetics-related health needs is discussion with the individual, family, or community regarding their goals in order to determine mutual genetics-related health outcomes.

II. Refer

Once the identification of a client who is experiencing or at risk for experiencing a genetic condition is made, gerontological nurses may find it necessary to refer their clients to other providers in order to assure the accuracy of diagnosis as well as to provide specialty genetics or mental health services.

Referral for Confirmation of Diagnosis

Accurate genetic counseling is dependent upon accurate diagnoses. Individuals or families may need referral to their primary care provider or specialist for a comprehensive evaluation of the condition of concern.

Referral for Specialized Genetic Services

Individuals or families meeting the criteria for referral for specialized genetic services can be referred to genetic specialists for further evaluation. A number of strategies can be used to locate genetic specialists in your area, including:

- Contact the genetics division of a regional tertiary care facility.
- Contact the State Department of Public Health for information about outreach genetic services.
- Visit the follow Web sites for information about contacting genetic specialists:
 - the [International Society of Nurses in Genetics Web site](http://www.nursing.creighton.edu/isong), www.nursing.creighton.edu/isong;
 - the [National Society of Genetic Counselors Web site](http://www.nsgc.org), www.nsgc.org

Once the referral is initiated, clients may be asked to release medical records to the genetic specialists prior to their evaluation. Following the evaluation, the referring provider will receive a summary letter of the visit including information provided to the client regarding the known inheritance of the condition as well as recommendations for follow-up care.

Referral for Specialty Mental Health Services

Individuals or families who demonstrate ongoing difficulty in processing and/or coping with genetic information may require referral to specialty

mental health services if their counseling needs are beyond the skills of the primary care provider or genetics specialist providers.

III. Support

The third key element of the gerontological nurse's role in caring for individuals affected by genetic conditions is the provision of ongoing support. This support may take the form of a general advocacy role or through more specific interventions such as reinforcement of specialty recommendations, teaching, psychosocial counseling, and follow-up assessments and goal setting.

Advocacy

Gerontological nurses are in important positions to advocate for their clients in relationship to genetics by assuring that clients are referred for comprehensive services; by assuring that clients are fully informed regarding genetic information, genetic testing, and genotype-based therapies; and by assuring that their client's genetic information, like other health information, remains confidential.

Reinforce specialty interventions

Gerontological nurses can review and clarify information and recommendations provided by the genetic specialist providers with their clients. Facilitation or implementation of specialist recommendations may be another important activity for gerontological nurses related to genetics services.

Teaching

In addition to clarifying information provided by other specialty providers, teaching related to a health condition or disease process, therapeutic options, and availability of resources is another potential nursing intervention for gerontological nurses supporting persons with or at risk for genetic conditions.

Psychosocial counseling

Individuals and families provided with new information about the genetics of a health condition may be faced with unique challenges as they synthesize the meaning of this information for their health and life planning. In addition, individuals who have sought specific genetic information through genetic testing are faced with both benefits and burdens of this information. Consequently, gerontological nurses can provide supportive psychosocial interventions such as coping enhancement, decision-making support, and family integrity promotion as clients sort through the meaning of genetic information for themselves and their families.

Ongoing assessment and goal setting

The chronic nature of many health conditions of elders as well as the lasting and multigenerational nature of genetic information necessitates that gerontological nurses maintain continuing contact with clients for assessment of outcomes and modification of the care plan based upon mutual goal-setting.

Identification, referral, and support are three important general nursing genetics interventions appropriate for all gerontological nurses. However, nurses who consistently work with clients experiencing known genetic conditions (such as Huntington's disease and Alzheimer's disease) may benefit from formal continuing education or advanced academic preparation in genetics nursing in order to provide basic and advanced genetics nursing interventions.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The recommendations were based primarily on a comprehensive review of published reports.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

- Identification, referral and support of elderly individuals affected by genetic conditions

Subgroups Most Likely to Benefit:

Those populations for which genetic testing or gene-targeted interventions are available (e.g., patients with Huntington's disease, patients with Alzheimer's disease, patients with breast cancer).

POTENTIAL HARMS

Potential psychological or emotional distress related to increased awareness of potential heritability of a disorder.

Subgroups Most Likely to be Harmed:

Any subgroup of patients within the stated target population.

QUALIFYING STATEMENTS

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This research-based practice is a general guideline. Patient care continues to require individualization based on patient needs and requests.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

The appendices in the original guideline document include strategies for implementation as well as tools to evaluate outcome and process factors following implementation.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Staying Healthy

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

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ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

1999

GUIDELINE DEVELOPER(S)

University of Iowa Gerontological Nursing Interventions Research Center,
Research Dissemination Core - Academic Institution

SOURCE(S) OF FUNDING

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GUIDELINE COMMITTEE

University of Iowa Gerontological Nursing Interventions Research Center Research Dissemination Core

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Author: Debra L. Schutte, MSN, RN.

Series Editor: Marita G. Titler, PhD, RN, FAAN.

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current release of the guideline.

An update is not in progress at this time.

GUIDELINE AVAILABILITY

Electronic copies: Not available at this time.

Print copies: Available from the University of Iowa Gerontological Nursing Interventions Research Center, Research Dissemination Core, 4118 Westlawn, Iowa City, IA 52242. For more information, please see the [University of Iowa Gerontological Nursing Interventions Research Center Web site](#).

AVAILABILITY OF COMPANION DOCUMENTS

None available

PATIENT RESOURCES

None available

NGC STATUS

This summary was completed by ECRI on November 19, 1999. The information was verified by the guideline developer as of January 20, 2000.

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